



# Resources for Families with Rare Diseases in North Carolina

## Health & Medical Resources in NC:

### North Carolina Community Health Center Association

NCCHCA promotes and supports patient-governed community health care organizations and the populations they serve. They envision every NC community having access to a patient-centered, patient-governed, culturally competent health care with high quality medical, pharmacy, dental, vision, behavioral health, and enabling services without regard to a person's ability to pay.

Phone: (919) 469-5701

<http://www.ncchca.org/>

### North Carolina Department of Health and Human Services

NC DHHS manages the delivery of health- and human-related services for all North Carolinians, especially for more vulnerable citizens – children, elderly, disabled and low-income families. The Department works closely with health care professionals, community leaders and advocacy groups; local, state and federal entities.

<https://www.ncdhhs.gov/>

### Health Equipment Loan Program (HELP)

HELP recycles donated medical equipment, restores the equipment, and loans it for reuse free of charge to any Durham County resident in need.

Phone: 919-471-7281

<http://www.projectaccessdurham.org/HELP/>

## Health & Medical Resources in the US:

### NIH - GARD (Genetic and Rare Disease Information Center)

GARD is a great resource for general rare disease support, the website includes many helpful articles.

<https://rarediseases.info.nih.gov/guides/pages/96/patients-families-and-friends>

### Baby's First Test

Baby's First Test provides great information on the importance and issues surrounding Newborn Screening.

<http://www.babysfirsttest.org/>

### **ProjectMEND**

Project MEND is committed to improving the quality of life for individuals living with disability and illness through the refurbishment, reuse and distribution of medical equipment and other assistive technology.

Phone: 888-903-6363 (MEND)

<http://www.projectmend.org/>

### **Supplemental Security Income (SSI) Benefits**

SSI is a program within the Social Security Administration that pays benefits to disabled adults and children who have limited income or resources.

<https://www.ssa.gov/disabilityssi/ssi.html>

### **Family Voices**

Family Voices is a nonprofit organization that promotes quality health care for all children and youth, especially those with special health care needs. This organization seeks to ensure that health care systems include, listen to, and honor the voices of families.

Phone: (505) 872-4774

[www.familyvoices.org](http://www.familyvoices.org)

### **Joyful Journey Mom**

Joyful Journey Mom offers a wide range of resources, such as lengthy lists concerning wish organizations, medical equipment, free gifts and services, and free places to go.

Email: joyfuljourney4me@gmail.com

<http://joyfuljourneymom.com/ultimate-list-of-grants-and-resources-for-families-with-special-needs/>

### **Rare Disease Report**

RDR provides numerous reports and articles on the news of rare disorders, it is a great way to stay informed on the issues and updates facing the rare disease community.

<http://www.raredr.com/>

## **Emergency Resources and Information:**

### **Food & Drug Administration (FDA) Disaster Info:**

The FDA offers helpful information for safe drug use after a natural disaster.

<https://www.fda.gov/Drugs/EmergencyPreparedness/ucm085200.htm>